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ABSTRACT

This report is part of a series of reports designed to document innovative daytime and supported living practices. It is based on a site visit to Katahdin Friends, Inc. (KFI) in March 1998. Since the mid-1980s, KFI, located in Millinocket, Maine, has transformed its supports for people with developmental disabilities from those that promote segregation to those that promote community inclusion and membership. KFI has transformed their preschool into an integrated preschool and closed the special purpose school, transferring children into regular public schools. In addition, they closed both the workshop and the day program, opting instead to support people in community jobs and other meaningful, integrated daytime activities. At the time of the site visit, the agency provided supported living services to 22 people and day services to 14 individuals. The first section of the report describes some of the key factors that facilitated conversion. The next section presents examples of community supports provided by the agency. A concluding section discusses key components to the conversion process, including a value base that plays a strong role in guiding decisions and actions, persistence, creativity, a focus on relationships, and collaboration. (CR)

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# Center on Human Policy

## ACTING ON A VISION:

## AGENCY CONVERSION

## AT KFI, MILLINOCKET, MAINE

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# ACTING ON A VISION: AGENCY CONVERSION AT KFI, MILLINOCKET, MAINE

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## ACTING ON A VISION: AGENCY CONVERSION AT KFI, MILLINOCKET, MAINE

Since the mid-1980s, KFI (Katahdin Friends, Inc.), located in the town of Millinocket, in rural, north central Maine, has transformed its supports for people with developmental disabilities from those that promote segregation to those that promote community inclusion and membership. KFI began in 1962 in response to the requests of parents whose children with developmental disabilities were not being served in the public schools. In the mid-1970s, the agency began offering adult vocational services for those who were no longer in school. For the first 15 years of its existence, the agency operated a number of facilities--a segregated preschool and a special purpose school, and later a sheltered workshop and a day program.

Then, beginning in the mid-1980s, the agency embarked on a path toward conversion from facility-based to inclusive services. Since that time, they have transformed the preschool into an integrated preschool; and, they closed the special purpose school, transferring children into regular public schools. In addition, they closed both the workshop and the day program, opting instead to support people in community jobs and other meaningful, integrated daytime activities.

Before they began the closure of the workshop and day program, the adults they served lived primarily with their families or in foster homes. The process of closing the workshop and day program led KFI to examine other aspects of the lives of people they supported. As a result, the agency began to offer different types of residential supports (e.g., as alternatives to family or foster homes, for those who so desired). Over time, they have developed the capacity to provide

intensive residential supports to enable a number of people with very significant disabilities to move out of institutions and into their own homes.

This report is part of a series of reports designed to document innovative daytime and supported living practices. It is based on a site visit in March 1998; the report reflects the agency at the time of the visit. At that time, the agency provided supported living services to 22 people, and day services to 14 individuals. The first section describes some of the key factors that facilitated conversion. The next section presents examples of community supports provided by the agency. A concluding section discusses lessons learned by KFI regarding agency conversion.

## TURNING POINTS: BACKGROUND TO AGENCY CONVERSION

Conversion did not happen all at once, but was a process that spanned several years (e.g., from the mid-1980s to the early 1990s). There were a number of important factors contributing to KFI's capacity to convert from facility-based to inclusive services. A few of these, summarized here, include: decision making based on values and vision; learning from others; looking at people's lives as a whole; and a commitment to continual learning. Each is discussed briefly below.

### Decision Making Based on Values and Vision

Many, many decisions, both large and seemingly small, contributed to the conversion at KFI. One staff member expressed that she felt their success was based on being able to take advantage of these decision points as opportunities for change: "We really changed by using opportunistic incrementalism. When we had decisions to make, we went in the direction of our

philosophy." The decisions and changes were not easy, and agency staff struggled at many different times.

"When we moved our day program from one building to another, should we take the soda machine? It was important to some people, but we didn't move it, because we wanted people to use the community." Later, in 1989, they made the decision not to do subcontract work. This was also a very difficult decision. "It was a heart-wrenching discussion. But, we didn't want to be the employer any longer. We asked, what is the value of this subcontract work? It is filling time. What a terrible reason to continue." Agency conversion, then, was a result of many combined decisions.

Learning from Others

Staff of agencies that have converted from segregated to inclusive services can often identify a few or multiple key turning points in this process. For KFI, one such point was in 1984, when they heard Lou Brown speak about supporting people in community jobs. They were excited about this possibility, and began educating themselves by gathering further information about agencies that were supporting people in the community.

Over time, conversion to inclusive services became a focus of the agency's mission. Although they did not know all the answers as to exactly how this would be accomplished, they were committed to figuring it out. In order to facilitate this process, they sought out information at conferences and in the literature about how to convert to community services.

Looking at People's Lives as a Whole

The initial primary focus on helping people work in the community led, over time, to a broader focus on looking at other aspects of people's lives, including supported living services.

> After getting out of the sheltered workshop business, we were still running the day center. But, we said, why do people have to come here? Because they don't live in their own homes. So, we began working to help people have their own homes, and provide support to them out of their homes, rather than a facility.

KFI also broadened its supports to encompass integrated daytime activities and involvements, in addition to employment. They recognized that people who were not working sometimes sat around all day with nothing meaningful to do, either at home or in segregated day programs. Additionally, those who worked most often worked part-time, and again spent much of the rest of the day in isolation or boredom.

At the same time, this focus on a wide variety of daytime involvements does not diminish the importance that KFI places on helping most people find paid jobs. Agency staff have been successful at finding paid work for many of the people they support. However, there are a number of people who they support who would like jobs but do not have them yet. Thus, a continuing challenge for the agency is to expand their capacity to find jobs for others who are seeking them, in ways such as creating additional job development positions, and/or encouraging all staff to see job development as part of their role.

Commitment to Continual Learning

The agency has continuously evolved in its learning about how best to support people in the community. For instance, initially, upon moving people out of the workshops, they used work crews and enclaves. However, they found these did not adequately match their vision of promoting true integration, and they began developing more individualized jobs and supports.

In addition, staff did not consider the closure of all of the facilities as an endpoint, but rather as a turning point enabling them to focus all of their energy on ongoing learning about the people they support and how best to support them in community life. The next section describes some examples of people who are supported by KFI.

## COMMUNITY SUPPORTS

KFI assists people to be a part of the community in multiple ways. Twenty-two people receive supported living services, which range from a couple of hours a week of support to 24 hours a day of support availability. KFI supports people who live with families, as well as individually or with a roommate. Some people rent these homes, while others have purchased them. The agency provides daytime supports for 14 people in integrated, individualized daytime pursuits, including paid and unpaid work, as well as a wide variety of social and leisure activities. Residential and daytime supports are provided through both state and Medicaid waiver funding.

This section first describes some supports provided by KFI to assist people who lived with families or in foster homes and were interested in having homes of their own. Some of these people were at risk for possible placement, sooner or later, in a group home or other

facility. It then gives some examples of support for daytime involvements. Finally, it describes supports for people with more intensive levels of needs whom KFI has assisted to move from institutions to their own homes.

From a Family or Foster Home to a Home of Their Own

KFI has supported a number of people to move from family and foster homes to homes of their own. Many of these people were always present in the community, going places and participating in community events and activities with their families. However, many of them had no real opportunity to pursue their own community connections and interests, or to participate in the community in meaningful ways.

KFI has assisted a number of people such as this to live in a variety of settings, including homes of their own (which they own or rent), shared homes, apartments, trailers, and so forth, with support for community participation. A few of the people who receive such supports are described below.

Steve. After living with his family all of his life, Steve, who is 51 years old and has Down syndrome, moved into his own apartment in 1995. He receives 21 hours per week of support from KFI for activities within his home and in the community. The phone in his apartment is a programmed push button phone, with pictures pasted on the buttons of people associated with each number. This enables him to both get help if he needs it, or to just communicate and connect with staff, family, and friends.

Steve's brother lives nearby and comes by to visit regularly. Over time, Joe's attitude about Steve having his own place has changed. He commented, "At first I was skeptical, but they have sold me on it." Joe is currently Steve's guardian; however, Steve would like to be his own guardian.

Steve's home is full of items reflecting his interests. His calendar includes pictures that he uses to plan and keep track of his schedule. Some of his favorite activities include going to church, exercising at a community fitness center, going to the library, taking walks, and attending a ceramics class. One of the shelves in his living room holds numerous ceramic figures that Steve has painted. Based on his interest in wildlife, these include a polar bear, wolf, loon, and others.

Since moving out of his family's home and becoming involved in more community activities, Steve's social network still includes family members, but has also expanded much beyond this. He has met a variety of people, in particular through church and the ceramics class. He met Diane, who is also supported by KFI, at church; they live near each other, have become friends, and enjoy visiting in each other's homes and taking walks together.

Having his own home has enabled Steve to have significant independence and control over his own life. Since moving out of his family's home, Steve's involvements have increased the dimensions of his membership in the community--a membership now based not just on family association, but also on his own interests and connections.

Mark and Tim. Mark and Tim, who are both supported by KFI, share a small home in Lincoln, Maine. In the past, Mark lived in an institution and then in foster homes; Tim lived

with his family and then in a number of foster homes. They first got to know each other when they were in the same foster home for a time.

Tim has both developmental disability and mental health labels, and has had difficulty in foster home placements because of his aggressive, sometime violent behavior. He had lived in a number of foster homes, and was at the point where a more restrictive placement was being considered. KFI initially supported Mark and Tim to live on their own, with supports. Later, they decided to buy a home together, and have lived there since 1994.

KFI provides them each with 12 hours of support a week, although staff often provide more than that if Mark or Tim are having a difficult time. Both men have held competitive jobs, though Mark is retired now. They receive support to do household maintenance, as well as community errands such as shopping, banking, and so forth. In addition, they receive support for various community involvements. For instance, at one time, Tim was a member of a local Singles Club. This club is now defunct, but he has now joined a community men's group and also bowls in a community bowling league.

Tim still has occasional violent episodes, but these are significantly less than in the past. KFI has helped both Tim and Mark establish emergency procedures for these times. When a problem arises, they either call the crisis hotline number or KFI staff for assistance.

Support for Meaningful Days

Staff at KFI feel that a meaningful day involves more than just paid work; it includes pursuit of interests, community connections, relationships, and other community involvements.

While they have assisted many people to find paid work, they have also assisted these people, as well as those who don't work, to enjoy meaningful, integrated days.

Craig. Craig, who has Down syndrome, is 25 years old, and lives with his mother in a trailer in the town of Lincoln, Maine. Two brothers have moved out, but live nearby and maintain regular contact. Some day Craig would like to move to his own place; but, for now, they are building a small addition to the trailer so Craig can have a bit more space of his own.

Craig's mother works a lot, but Craig is quite self-sufficient, doing a lot of cooking on his own, and getting around town to do occasional errands. Until the past few years, however, Craig had not had much opportunity to develop community connections through the pursuit of various interests.

His life has changed significantly through his involvement with a Community Advocate from KFI, who provides support for 4 hours a day, 5 days a week. Craig wanted to "get fit." So, they first began walking together, and then joined the local gym. Craig began spending time lifting weights, swimming, and taking karate lessons. Over time, he has advanced to the point of serving as a personal trainer for others at the gym, and is working on his brown belt in karate.

Other community involvements include taking guitar lessons and looking for a job, possibly in woodworking, which is an interest of Craig's. His guitar lessons have led, also, to a close friendship with his guitar teacher.

Craig's efforts have given him much more energy and self-confidence. He has since become involved in self-advocacy and ran for an elected position in the statewide self-advocacy

organization. His involvements have expanded his participation within his community, providing for him not only community presence but valued roles and relationships.

Ben. Ben, who is in his early 20s, rents his own apartment in a renovated schoolhouse in Bangor. After sustaining a head injury, he first received supports from an agency that focuses on supporting people with head injury. This agency helped arrange for Ben to share a trailer with another person who was supported by another agency. From the perspective of Ben's parents, the other agency was not supporting that person well in the home, so it was often messy. Also, they felt that Ben didn't receive enough support on the weekends, and had too much free time. From the perspective of Ben's mother, "It was extremely stressful, for Ben and the family." Then, as she put it, "Things went from bad to worse" when a couple of Ben's friends moved out of town. His parents were concerned about his increased drinking and spending lots of money. They tried to talk to the agency about helping Ben find a new place to live, and find more for him to do on weekends. The head trauma agency suggested some boarding homes, but none were satisfactory to Ben or his parents.

At this point, Ben returned to East Millinocket to live with his family. However, he wasn't happy there, as "there wasn't enough to do." The family approached the head trauma agency again, which only offered a group home for Ben.

At this time, Ben became eligible for Section 8 housing. His parents lobbied a legislator to get some funding, through KFI, to support Ben. With this in place, Ben moved into his own apartment. He receives 31 hours of support per week, provided by two young men employed by KFI. They help him with things such as paying the bills and shopping. They have also helped

him explore interests in his home and in the community. He has a computer, on which he enjoys playing computer games, sending e-mail, and sending cards. Recently, he took an adult education computer course. Also, three days a week, Ben volunteers at the Humane Society; someday, he would like a paying job there. Since none is now available, he is exploring other possible jobs, such as at video or music stores, with the assistance of his support staff. There is a gym in the apartment building, and Ben enjoys working out there on a regular basis, sometimes on his own, and sometimes with one of his Community Advocates.

An Opportunity to Live in the Community Versus a Facility

Beginning around 1992, KFI began serving people with more intensive needs, including those who require availability of supports 24 hours a day. This was, in part, in response to the state's request for them to support a few very vulnerable people who were in a state or private institution. It was also in response to families and other advocates who knew of KFI's philosophy of supporting people in the community and brought people to the attention of KFI. Unlike those who lived with families, these people have been isolated from the community, at least periodically, and sometimes for years.

Bernard. Bernard, who is 49, was originally from Lincoln. After his mother's death, when he was 10, he lived in an institution for 34 years and an ICF/MR (Intermediate Care Facility for the Mentally Retarded) for 4 years. KFI was interested in supporting Bernard to return to Lincoln, where he still has relatives. In fact, a few of his cousins have worked for KFI and never knew of his existence before the agency became involved in bringing him home.

Since 1997, KFI has supported Bernard to live in his own apartment, located within a small apartment complex not far from the center of town. Bernard receives 24-hour a day supports, provided by three different people, one of whom provides 72 hours of support, another 56 hours, and another 40 hours. A critical feature of support for Bernard is his nutritional needs and dietary restrictions related to phenylketonuria (PKU). In the ICF/MR, this was addressed, in part, through locks on the refrigerator. Also, his support staff person commented that, "When he first moved here, he used to eat standing up, like he was starving." Bernard's refrigerator in his apartment is not locked, and he eats sitting down, with staff support and assistance, when needed.

Although Bernard does not communicate verbally to a great extent, he has many ways of expressing feelings and preferences. In the past, when he had little control over his life, many of these were interpreted as "negative," and he would have been labeled as someone with challenging behaviors. However, many of these behaviors have diminished or disappeared completely since KFI has supported him to live in his own place and has been responsive to his communication. For instance, if a support staff person has turned out not to be a good match for Bernard, the agency has helped Bernard seek others who are more compatible.

Since he has been supported at KFI, staff have focused on helping Bernard identify interests, assisting him to participate in the community based on these interests, and assisting him to develop a social network. At home, Bernard enjoys sitting in his rocking chair and listening to classical music. Outdoors, he enjoys spending time by the water, and going into town to shop or visit the barber. He has been reunited with family members, including his father and cousins, and they exchange visits. In addition, he maintains a friendship with a woman who used to

provide support for him. Staff are also working with Bernard on establishing other community involvements and connections.

Katie. Katie has lived in her own apartment in Millinocket since the Fall of 1997. Previously, she lived in a residential treatment center for people with mental health labels. KFI is currently funded to provide 30 hours of support a week to Katie, although, according to staff members, they typically provide about double that amount. In order to support Katie, though, it was particularly important that the amount of supports be flexible, in response to her changing needs. For instance, when she first moved in, she was afraid to stay overnight alone, so the agency patched together funding for 24-hour supports. Over time, she became comfortable and no longer needed this level of support.

In supporting Katie, it is key that the agency collaborates with people in the mental health system. KFI staff assist Katie to travel 65 miles on a regular basis, so she can maintain contact with her mental health counselor. In addition, at crisis times, they have helped her travel to a treatment center where she has established connections and relationships. The agency also supports her to maintain contact with her mother and grandmother, who live about an hour away.

For Katie, and for some of the other people who the agency supports, staff have had to balance promoting community involvements versus helping people feel comfortable in their own home. As one staff member put it, "She really needed to make a safe home, before she was ready to get out a lot." After about 6 months, she started to call this home.

Staff have made efforts to assist Katie to become involved in community activities. She has expressed initial enthusiasm for some, but seems to quickly lose interest. In addition, staff

have worked on developing their own relationships with Katie, as well as helping her establish other community connections. In the past, she has had some negative experiences with relationships; so staff are working particularly hard to help build some positive experiences.

## LESSONS

Over the course of their conversion, the agency has learned many lessons about the closure of facilities and development of individualized community supports. Some key lessons are summarized below.

**1. The need for continual examination of values and decisions.** Having an agency mission and values that support inclusion are not enough, in themselves. In a process of agency conversion, KFI held every decision, whether large or seemingly small, up to the mission and values. At the same time, they recognized they would not be able to implement an ideal vision--that there would be tradeoffs and compromises involved. In light of this, they advised others in the midst of agency change to at least recognize and acknowledge the compromises. As one staff member put it, "Know when you're compromising; but don't start with a compromise."

In the coming years, KFI will be faced with increasing pressures to expand its services in order to get more revenue for the agency. In addition, because they have a reputation for delivering quality services, increasing numbers of families and people with disabilities are seeking KFI's services. The challenge, for the agency, will be to continue to hold up each decision to its values, so they can maintain the capacity of their agency to be an individualized, flexible, and responsive organization.

**2. The importance of finding and/or working to create flexibility within funding and regulatory systems.** In this day and age with tight fiscal environments, it is not easy for any agency to support people with severe disabilities in individualized ways in the community. The approach of KFI has been to make plans with people, with a commitment to figuring out how to implement them, rather than letting the planning be driven by fiscal and regulatory issues. At the same time, increased flexibility within the system can greatly facilitate the provision of individualized community supports. Thus, KFI staff have worked on their own and in collaboration with others to find and create flexibility within the system, in many ways, including those described briefly below:

Obtaining supplemental funding. In order to close the workshop, they were helped initially to begin community employment services by a state grant. Later, federal and state grants (e.g., a federal grant to promote transition from school to adult services; a state organizational change grant) also helped them expand their community supports.

Retaining some flexible funds. It is sometimes tempting, and sometimes necessary, for an agency to trade in its state dollars for Medicaid dollars. However, the state dollars generally allow a much broader range of supports. Thus, KFI has been conscious about keeping a good balance of both Medicaid and state funds.

Obtaining bridge funding for conversion. During the process of conversion to community services, it is often important for agencies to have some bridge money available (e.g., to help with start-up costs for supports for people in new settings, etc.). KFI was able to arrange with the state Bureau of Rehabilitation to obtain an equivalent fee-for-services amount for people they

supported, even if the specific units of service decreased, which provided some bridge funding for the agency transition.

Negotiating with the state for more flexible hours for daytime supports. Initially, daytime supports for people were all within the 9:00 a.m. to 3:00 p.m. time frame. Staff at KFI identified the problem as follows: "The state was defining daytime services as a day; we requested them to define it in terms of hours, so we could do things at any time." The state agreed to this change. So, now, supports can be provided anytime between 7:00 a.m. and 9:00 p.m. This gives much more flexibility for KFI staff and the people they support in figuring out individualized daytime options.

Combining residential habilitation and day habilitation funding. With combined funding, there is no separation between day and residential staff. This results in costs savings in the overall costs of supports for a given individual. It also makes it easier to provide flexible daytime supports (e.g., without people having to be out of their homes for specific hours every day).

KFI's ability to find this flexibility is, in part, enhanced by its positive, collaborative relationships with others, as described below. While they have been very creative in dealing with fiscal and regulatory issues, staff at KFI acknowledge that the system still does not provide incentives for the kind of work they are doing. Thus, they face the ongoing challenge of struggling against systems barriers and disincentives.

**3. The importance of collaboration.** KFI's collaborative relationships with many individuals and organizations is a great asset. They have identified people at the state level who

are creative and flexible in their use of the Medicaid waiver. In addition, they have cultivated positive relations with a variety of state-level people, based in part on KFI's reputation of accomplishing what it commits to, and doing so in a quality manner.

The connections that KFI staff have forged with other disability service agencies enhance the support that is provided to people. For example, their close collaboration with people in the mental health field is critical to their support of people with developmental disability and mental health labels.

**4. Recognition that space defines what you do; thus, the determination to proceed with closing the facility, despite their own uncertainties and lack of answers for everything.** Administrators at KFI were aware that if they maintained special, separate places, they would end up using them. They realized that they could not promote inclusion with a dual system of services. Thus, they made a commitment to follow a path toward complete facility closure.

Doing this was not without some risk. Some vocal people in the community were upset by their closure of the facilities. Staff also worried about their own jobs, wondering if closure of the facilities would lead to elimination of their jobs altogether. In addition, when they made the commitment to closure, they didn't know all the answers as to how it was going to be accomplished; however, along the way, they spent time learning from others who had also closed facilities, as well as learning from their own actions and experiences. While staff at KFI have learned a tremendous amount over the last several years, a strength of the organization is that they don't consider themselves as having all the answers now, but see themselves as continually learning about the people they support and how best to assist them.

**5. The importance of a focus on relationships.** It is key that a focus on relationships pervades all of the work of KFI. This includes relationships of many types:

- Relationships between staff and the people they support. The relationship between staff and the people they support is seen as being critical to the support. Overall, KFI staff appear to have close, committed, trusting relationships with those they support. At times when there is not a good match, changes are made in order to find a better match. They recognize the challenge of not becoming the sole safety net or social network for a given individual. They are concerned both about some people they support becoming overreliant on staff, and about some staff having trouble letting go of people. This does not prevent them from encouraging staff to build close, caring relationships; however, it reminds them of the need to continually work to expand people's networks beyond staff, as well.
- Staff relationships with families. KFI staff strive to help people maintain relationships with their families, and have helped some people reconnect with family members who had been out of touch. In addition, KFI staff feel it is important that they try to have positive, working relationships with families. While they have done this in many instances, they also feel, at times, that they could do more in terms of working with families and involving them in planning and other aspects of people's lives.
- A wide variety of relationships for people who are supported by KFI. Some of the people who KFI supports had long-term, close friendships with others with

disabilities in the workshops. In the field of human services, sometimes this is used as a rationale to keep workshops and other facilities open. KFI staff felt that this was not a reason to keep the workshops open. However, they do feel that it is important to value and honor these relationships, and support people to maintain them, through visits, calls, small gatherings, and so forth. At the same time, KFI staff feel it is equally as important to assist people to have opportunities to get to know and spend time with community members who are nondisabled. Thus, a significant amount of staff time and energy is focused on thinking of strategies to promote diverse community connections and social networks. KFI staff themselves have forged positive relationships with many community groups, organizations, and individuals, and this serves as a positive link to the community for some of the people they support.

- Relationships between staff. A strength of KFI is the emphasis that is placed on development of positive relationships between staff. As a result, overall, staff seem to feel supported by and invested in the agency. Many have made long-term commitments to the agency, as well as to the people they support.

Overall, KFI has helped many of the people they support to develop diverse community connections and relationships. At the same time, as in many other agencies that give priority to supporting people in community connections and relationships, some of the people they support are still relatively socially isolated. Thus, a challenge is the ongoing work of relationship-building and community-building.

## CONCLUSION

Through its conversion, KFI aimed to move from services that promoted segregation or simply community presence, to services that assisted people to lead rich, meaningful lives in the community. The lessons of their experience suggest that key components to this process include--a value base that plays a strong role in guiding decisions and actions, persistence, creativity, a focus on relationships, and collaboration. All of these components, combined, have facilitated an organizational transformation that now enables KFI to assist people not only with community presence, but to have meaningful community involvements and connections, which are keys to true community participation and membership.